



# Roadmap for Researchers:

Navigating the Research  
Process with an Equity Lens

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# FOREWORD

## Why Develop a Roadmap for Racial Equity Research?

Researchers increasingly recognize and acknowledge the influence of racism, historic injustice, and deeply embedded biases in the research enterprise. After beginning to see things differently or looking for ways to have more influence on promoting health equity, many ask themselves how they should change the way they do their own work and how to provide leadership and training opportunities within their organizations and multidisciplinary networks.

Taking this next step can be challenging – even overwhelming -- given the rapidly changing research ecosystem and multiplicity of information sources about promoting racial equity. Where do you start and how do you proceed? Without being able to foresee how much change will be needed and by whom, or to understand how long it will take, you might be looking for examples from other people, organizations, and communities who seem to be on a path toward equitable research.

You may already be looking for different people to work with. They may be able to help you orient yourself, deepen your commitment to equity, and begin to navigate differently, whether as mentors, partners, or mentees. They may be able to help you distinguish between respecting and centering others' opinions without appropriating them. But who are they, and how will you find them? How will you acknowledge their influence as you exchange information, receive and provide advice, and engage with each other?

This Roadmap is a response to requests from the AcademyHealth Board of Directors and members, as well as our work partners and other colleagues, to provide actionable and evidence-based guidance on advancing racial equity research. We built on the 5 areas of action recommended by an external advisory group report on [Advancing Diversity, Equity, and Inclusion in the Health Services and Policy Research Workforce](#), which was released in June 2021. More specifically, the group recommended elevating the importance and visibility of health equity research by creating a collaborative guidance document, including a glossary of terms to build a shared language.

**This Roadmap provides actionable and evidence-based guidance on advancing racial equity research. Our aspirational goal is to help create an intersectional community that encompasses all dimensions of diversity and includes a wide variety of experience, ideas, and perspectives.**

Based on the available evidence, discussions with several people in our research and policy communities, and our organizational experience, the Roadmap reflects a synthesis of thought leadership and promising practices. It includes the work of those who propose new research and cognitive frameworks and new language as well as those who represent emerging views about the value of lived experience in the research enterprise. Cited sources include organizations and individuals who are in various stages of their own racial equity journeys; who come from different disciplines and perspectives; who work in different settings and geographies, ranging from academic and clinical systems to public health policy and practice; who conduct and apply different types of research methods; and who generate and use different data sources.

Taken as a whole, the body of work on racial equity challenges us to interrogate and deconstruct the legacy of structural racism and address the impact of our past and future work on individuals and communities who have been marginalized by white research culture and practices. We acknowledge there are multiple experiences of discrimination and many excluded and marginalized people who have been discriminated against based on ability status, gender identity, sexual orientation, age, language proficiency, geography, country of origin, income, housing, social position, and other factors.

The term racial equity is used throughout the Roadmap because AcademyHealth made an organizational commitment in 2020 to **center racial/ethnic diversity, representation, and inclusion in our work**. Our aspirational goal is to help create an intersectional community that encompasses all dimensions of diversity and includes a wide variety of experience, ideas, and perspectives.

## How to Use the Roadmap

The Roadmap is organized into ten steps that occur across the research lifecycle, from forming your team and developing your ideas to disseminating your findings and reflecting on what you learned. If you are a researcher, a member of a research team, an educator, an executive team member, a program officer, funder, industry partner, or other thought leader, the Roadmap might be used as a discussion guide to help broaden your team's usual approaches to research and be more intentional about change.

Each of the ten steps includes a contextual overview of the step, questions for your team to answer together, and references and resources for further study. Some of the steps are non-linear and can be taken in parallel as the context requires. Rather

than including detailed discussions of technical and methodological issues, the focus is on the steps where a racial equity lens may be most crucial, most challenging to implement, and more likely to be forgotten or incompletely applied.

**The Roadmap is not meant to be didactic but is rather a tool to inform planning.**

The Roadmap is not meant to be didactic but is rather a tool to inform planning. Through a series of questions that correspond to each stage of the research cycle, the Roadmap can help to better ensure the consistent use of a racial equity lens. The questions are not exhaustive and serve as a starting point to stimulate awareness, discussion, and action.

We are grateful for support and encouragement from The Robert Wood Johnson Foundation (RWJF). We created the Roadmap through grant support along with coaching and training sessions from the RWJF Equity Learning Lab. We look forward to your feedback and invite you to send your comments and suggestions to [DIME@academyhealth.org](mailto:DIME@academyhealth.org).



# Section I:

## PLANNING: BUILD AWARENESS AND INTENTION

“Racism is more than interpersonal discrimination or implicit bias toward people of color; it encompasses racist practices and systems that are embedded into institutions in the United States.”

– Paris B. Adkins-Jackson, Tongtan Chantarat, Zinzi D. Bailey, and Ninez A. Ponce, *American Journal of Epidemiology*, 2021

### STEP 1: Make a commitment to equitable research practices.

Even for people who study health disparities, the full impact and ongoing nature of structural racism continues to be a challenge for them, their communities, and society to reckon with. When an organization’s leadership and colleagues fail to acknowledge privilege, disregard history, and do not appreciate the value of diverse lived experiences, they perpetuate structural racism and the systemic biases of previous generations. Often without realizing it, they create environments where people of color and those from historically marginalized communities do not feel welcome, seen, or valued (Boyd et al., 2020; Hardeman & Karbeah, 2020; Plough, 2022; Robert Wood Johnson Foundation 2023; Urban Institute DEI Council, 2020).

**For those who are feeling unseen and undervalued, the chronic dismissal and ignorance of their expertise, perspectives, and talents and their lack of opportunities to advance because of structural racism is discouraging. It also impacts mental and physical health**

The [Workplace Culture Study](#) (Chantarat et al, 2023) found that individuals from historically and structurally excluded groups said they had experienced professional discrimination within the health services and policy research (HSR) field, even though they also had seen a growing commitment to increasing workforce diversity and improving equity and inclusion in the workplace. In another example of structural exclusion, a [study](#) of more than one million papers from six publishers over the past two decades found geographic and racial disparities in editorial board representation, time spent in review, and citation rate (Liu et al., 2023).

Federal funding for scientific research also reflects systemic racial biases. Racial disparities in grant funding at NIH have been [documented since 2011](#) (Ginther et al, 2011) and [funding gaps remain despite efforts to mitigate bias](#) (Taffe & Gilpin, 2021).

For those who are feeling unseen and undervalued, the chronic dismissal and ignorance of their expertise, perspectives, and talents and their lack of opportunities to advance because of structural racism is discouraging. It also impacts mental and physical health (Williams et al., 1997; <https://scholar.harvard.edu/davidrwilliams/node/32777>; Mohottige, Davenport Bhavsar et al., 2023).

Among those who want to begin or renew a commitment to creating and maintaining a collaborative work culture and conducting research with a racial equity lens, the following considerations are essential:

- Read different sources and perspectives on foundational principles and practices of racial equity, including fields outside of health care, such as ethnic studies and sociology.
- Acknowledge your own and your team’s implicit biases and develop strategies to address and mitigate them.
- Explore your personal and team positionality in terms of what systems influence your identity and your approach to research.
- Define and seek out interested parties whose experiences you can learn from.
- Center the groups who previously have been and might still be marginalized.
- Maintain a sense of openness to different perspectives and humility about the learning process.
- Use inclusive language (see [AMIA, 2023](#); [CDC Global Health Equity, 2022](#); [Urban Institute DEI Council, 2020](#)) and establish a shared vocabulary for health equity.

# QUESTIONS

1. Have you reviewed health equity research or policy frameworks? One or more of the following resources may be helpful, depending on your goals and priorities (presented alphabetically by authoring organization):
  - Digital Healthcare Equity Framework (AHRQ);
  - Racial Equity and Inclusion Framework (Annie E. Casey Foundation)
  - Equity Action Framework (BUILD)
  - Equitable Evaluation Framework (Equitable Evaluation Initiative)
  - Racial Equity and Policy (REAP) Framework (Commonwealth Fund)
  - Public Health Critical Race Praxis (PHCRP)
  - Racial Equity Impact Assessment Toolkit (Race Forward),
  - We All Count Project for Equity in Data Science
  - Global Indigenous Data Alliance (GIDA) CARE Principles
  - Are there others you'd like to tell us about?
2. Are you and your team familiar with and do you accept the premise of centering and recentering marginalized groups? (See [University of Minnesota Libraries](#))
3. Have you engaged with the groups of people who will be impacted by your work about their preferred ways to measure their identities and experience?
4. Have you and your team members ever taken an **implicit bias test or received diversity and inclusion training?** (see [Project Implicit](#))
5. Are you a member of **Data Across Sectors for Health (DASH), Partners for Advancing Health Equity Collaborative (P4HE), We All Count, The Dartmouth Health Equity Atlas** working group, **the UCLA Data Equity Center**, or other health equity coalitions or learning communities?
6. Are you engaged with Employee Resource Groups, DEI Coalitions, Community Engagement Teams, or other groups where you live and work?



“It is insufficient to simply change representation (diversity); workplace climates must also affirm the positive contributions of increasing diversity and create conditions in which those from historically excluded groups can thrive.”

– Tongtan Chantararat, Taylor B. Rogers, Carmen Mitchell, Michelle Ko, *Health Services Research*, 2022

## STEP 2: Form a representative team that values communication, inclusion, and good management.

One of the most concrete and visible changes in research culture is creating more opportunities to work with teams that reflect diverse perspectives, backgrounds, racial/ethnic identities, and lived experience. The ease of achieving team and workforce diversity depends on a variety of systemic factors, including institutional hiring practices, the culture and history of the geographic area surrounding the organization, the openness of leadership to promoting diversity, the degree of representation of leadership, the amount of turnover creating openings, requirements of funding sources, and extent of public commitment and recognition for diversity, among others.

**Community-engaged participatory researchers have demonstrated a variety of management and communication strategies that engage partners in inclusive ways**

Evidence from management scientists suggests that more diverse teams with a broader range of skills and areas of expertise can outperform less diverse teams (e.g., Neuroleadership Institute, 2021; Pentland 2010). However, teams also tend to perform better when the team members are valued by management and each other and the culture is more collaborative than competitive (Gratton & Erickson, 2007; Meade 2021).

For equity researchers who are familiar with a variety of frameworks and methodological approaches and want to build a diverse team, discriminatory institutional recruitment and hiring policies and practices and lack of attention to retention strategies can be restrictive, discouraging, and disheartening. How much do these researchers speak out about systemic bias, how explicit can they be, and what kinds of retaliation might they expect? Where will they find allies and opportunities to build and sustain a diverse team? (Plough, 2022). Many resources encourage people to have “courageous conversations” about the challenges they face around diversity and inclusion (e.g., AAUW 2023; Plough 2022).

At the national level, the Agency for Healthcare Research and Quality (AHRQ) has established **Engagement, Leadership, and Research Management** as one of 8 domains of Core Competencies for Health Services Researchers in Learning Health Systems. The newest addition to the competencies is **Health and Healthcare Equity and Justice**. While some fellowship programs funded by AHRQ and the VA emphasize these competencies, they are not embedded in most HSR training programs and there are no standardized curricula yet.

In some institutions, executive management education courses and certificates through business and management schools provide adjuncts to formal technical training (e.g., **Data-Driven Teams** course at the MIT Sloan School of Management, **Harvard’s course on Inclusive Leadership for a Diverse Workplace**, the **Wharton Program for C-Suite Executives**, **Stanford Leadership Program**, or many others).

Community-engaged participatory researchers have demonstrated a variety of management and communication strategies that engage partners in inclusive ways (Horowitz et al., 2019; Javier et al., 2010; Martin-Kerry et al., 2023; Moreno et al., 2009; Sankofa et al., 2021). The teams that work collaboratively with community partners also tend to work more collaboratively with each other, as compared to traditional research teams that are more hierarchical (Ohio University, 2023).

**Team-building and change management usually start with small steps and there is no one single, perfect way to make things happen.**

Team-building and change management usually start with small steps and there is no one single, perfect way to make things happen. There are many ways to diversify team perspectives, such as engaging with community members, setting up joint training with other teams, or recruiting consultants and coaches. With an intentional commitment to work collaboratively and a clear management plan, good governance (i.e., clarity about team and partner roles, responsibilities, and decision-making), and ongoing communications across the team and partners, culture change begins.



# QUESTIONS

1. What core concepts about racism and equity do you and your team members need to understand more deeply? Have all of your team members made a commitment to this work during the project launch meeting?
2. How are people from different racial and ethnic groups differentially affected by the issues you propose to study? How are they involved in developing research questions?
3. Does your team decision-making process reflect diversity in racial/ethnic identity, areas of expertise, and career stage?
4. Who needs to be recruited or invited to join your team and/or to advise you?
5. What plans have you made to include payments for partners and research participants in your budget? How will you help to support their time (e.g., honoraria, protected time, salary support)?
6. Are you using or have you developed a glossary to help promote the use of shared language across a team with different areas of expertise and experience?
7. What is your current recruitment and hiring process and plan for promoting diversity? If there are barriers to diversity hiring, how else can you integrate different perspectives (e.g., external advisory groups and reviewers)?
8. In promoting diversity in various roles, what is your process for coaching and developing current staff to take on leadership roles in the work?



# Section II:

## PREPARATION: FRAMING YOUR RESEARCH QUESTIONS INCLUSIVELY

“What will it take to deeply embed equity in the data, evidence, and knowledge that fuel change?”

– Alonzo Plough, *Culture of Health Blog*, RWJF Nov 10, 2022

### STEP 3: Collaborate in developing clear objectives and research questions.

Strong communication, management, and team-building skills are essential to high-performing groups (Friedman, 2021). These skills are rarely taught formally in research programs and tend to be learned on the job. This informal approach may perpetuate structural forms of bias and discrimination and may hinder a team’s ability to collaborate internally through efficient and inclusive decision-making and workflow (Chrobot-Mason et al., 2020; Hawn Nelson et al., 2020). It also may influence the ways team members study race and ethnicity and engage with external experts in racial equity when developing research questions.

**The process of acknowledging the privileges and biases of whiteness can start with teams through collaborative decision-making, power-sharing, and being explicit about calling out and naming biases.**

Gender and racial gaps in leadership of US universities are well documented: university leadership tends to be white, male, and older. Nearly 75% of university faculty are white, according to the [National Center for Education Statistics](#) at the US Department of Education. In 2022, a national study of 130 major public and private universities found that only 22% had a woman in the top leadership position (e.g., president, chancellor or system head) and only 26% had female board chairs (Nietzel, 2022). Black women make up 14% of female college or university presidents and Black men are 13.3% of all male college or university presidents (American Council on Education, 2023; Lockett et al., 2018).

The process of acknowledging the privileges and biases of whiteness can start with teams through collaborative decision-making, power-sharing, and being explicit about calling out and naming biases. Whether within teams or with partners, everyday biases are not limited to racial/ethnic preferences and can include gender identity, age, disability status, country of origin, language proficiency, and institutional and educational biases, among others.

**We have sought to identify resources that provide practical suggestions to support the kinds of culture change that promote racial equity and inclusion in research.**

More broadly, participatory governance that centers racial equity and recognizes historical context tends to increase the sense of inclusion (AECF, 2015; Hawn Nelson et al., 2020). A related approach, asset mapping, focuses on assets and aspirations before naming challenges and deficits (Martin-Kerry et al., 2023). The [California Health Care Foundation](#) (2021) provides guidance to proposal authors about using an asset-based approach, with specific suggestions about language and framing that promote a sense of respect and inclusion among community partners and define communities by their assets and aspirations before noting challenges and deficits.

Developing relationships and engaging in joint decision-making with community partners and listening and responding to their feedback is an integral part of the culture of community-based participatory research (Damian et al., 2020; Polk et al., 2019; Sankofa et al., 2021) and community-engaged research teams (Key et al., 2019; Sankofa et al., 2021). Similarly, the importance of community voice is recognized in community engagement initiatives across policy domains and levels of government (Farrell et al., 2021).

The [Community Engagement Studio Toolkit](#) developed by the Meharry-Vanderbilt Community Engaged Research Core (Israel et al., 2019) provides a step-by-step guide that shows how intentional awareness and mutual respect can alter the course and community impact of research projects. The Toolkit and other resources and references listed in the Roadmap have informed the development of suggestions and questions that may apply across a variety of research teams and settings at various stages of the research lifecycle.

Several of these resources include multi-sector collaboration guidance from minority-serving institutions (MSIs), community-based organizations, and other organizations on greater inclusion of pronouns, language access/translation resources, cultural resonance, and using asset-based rather than deficit models. We have sought to identify resources that provide practical suggestions to support the kinds of culture change that promote racial equity and inclusion in research.

## QUESTIONS

1. If you are new to studying racial equity, are you collaborating with more experienced researchers and other experts?
2. Are you using inclusive language to describe the specific problems your study will be addressing?
3. Are you seeking funding that will support community engagement and partnerships?
4. Can you describe the policy context and root causes of these problems? What upstream factors contribute to those disparities, and how will your research frame and address them?
5. How are those problems worse for people of color or other underrepresented groups?
6. Have you avoided framing the problems from a deficit model? How will you be using an asset-based framework?
7. How can you include representation from the communities you will be studying in developing your research questions?
8. How can you be sure the information from your study will be shared effectively with partners and communities?
9. Have you considered how your findings can benefit the communities you are studying?



“Building data infrastructure without a racial equity lens and understanding of historical context will exacerbate existing inequalities along the lines of race, gender, class, and ability.”

— Amy Hawn Nelson, Della Jenkins, Sharon Zanti, Matthew Katz, Emily Berkowitz, TC Burnett, & Dennis Culhane, *Actionable Intelligence for Social Policy (AISP)*, University of Pennsylvania, 2020

## STEP 4: Diversify references and data sources.

Most researchers rely on a core set of familiar references to establish the credibility of new work. Building on prior work is a time-honored tradition within the scholarly enterprise and it helps to provide continuity and show how new knowledge contributes to general knowledge, domain-specific knowledge, and the public good. What often goes unsaid is the extent to which published literature and existing data sets reflect white culture and biases, and how much work it will take to reconcile the use of flawed data about race, racial identity, and ethnicity.

To begin to address these structural issues, professional guidelines for reporting race and ethnicity have been suggested by the [AMA and AAMC](#) (2021), [JAMA Network](#) (Flanagan et al. 2021), [Grantmakers in Health and NCQA](#) (2021), and government agencies, including the [Canada Research Coordinating Committee](#), and the [Equitable Data Working Group](#) (2022). [AMIA](#) (2023) has released inclusive language and context style guidelines for researchers and their partners to promote greater transparency and openness about how research is conducted, and the [Urban Institute DEI Group](#) provided guidance for its own researchers that was later shared more broadly with the larger research community.

### Published literature and existing data sets reflect white culture and biases.

The [American Heart Association](#) has called for research that examines the intersectionality and combined impact of discrimination on the health of communities and individuals, requiring new methods and data sources and more collaborative approaches across the research lifecycle. Examples of these approaches can be found in studies by health equity researchers using mixed-methods, community-engaged approaches (e.g., Damian et al, 2018; Damian et al, 2017; Held (2019); Javier et al., 2014; Ponce et al., 2023).

An emphasis on racial equity can challenge assumptions about established knowledge. This begins with the way we review previous published literature and value certain publications over others and continues

throughout the research process to publication and dissemination (Krieger, Boyd, De Maio, Maybank, 2021). Given that structural biases and racism are embedded in every step of the process, researchers can start with small steps that help to erase invisibility of marginalized groups and promote awareness of a broader range of scholars and experts.

### An emphasis on racial equity can challenge assumptions about established knowledge..

For example, the [University of Minnesota medical librarians' guide on anti-racism research](#) suggests ways to identify underrepresented and marginalized researchers who have different professional training, institutional affiliations, and lived experience. Another way to reduce citation bias is to add a Citation Diversity Statement to publications, usually just above the references section (Zurn et al., 2020; Dalhousie University Libraries, 2023).

Here are some concrete steps to acknowledge and expand the diversity, numbers, and types of references included in research publications.

- Work with medical librarians when possible to broaden your awareness of scholars and studies who examine your area of interest from different perspectives and use different methods and data sources.
- Review and cite a broad range of literature, including work by scholars of color whose work may be represented in smaller, more specialized databases outside of the usual biomedical sources such as PubMed (See U of Minnesota Libraries guide, 2023).
- Establish communication guidelines and/or style guides for culturally resonant, non-triggering, and inclusive language that reflects the values of the communities you are studying (See Canada Research Coordinating Committee (2022)).
- Broaden your perspective to include more graphic representations, photos, and videos that are culturally resonant and help to convey concepts that do not rely on written text and translation.

# QUESTIONS

1. How will you use inclusive citation practices?
2. Have you cited and given credit to experts of color who defined originating concepts and whose work addresses your research questions and context?
3. What communications guidelines are you following or developing with partners and community members?
4. Have you assessed and acknowledged the limitations of the data you will be using and how you intend to address those limitations?
5. Have you considered using data bases and search strategies that are outside of biomedical research and your primary field of expertise?
6. If you are conducting primary research, how do you plan to address the potential for harm and conflict of interest from the historically marginalized individuals and communities you're studying?
7. If you are conducting primary qualitative research, have you considered ways your research design can make participation more accessible for diverse communities, such as including multilingual interviewers, translation services, and recruitment materials in different languages?
8. How will you be sharing your work beyond the written word to make it more accessible to everyone?



# Section III:

## IMPLEMENTATION: DATA MANAGEMENT AND GOVERNANCE

“I see being eliminated in the data as an ongoing part of the continuing genocide of American Indians and Alaska Natives. If you eliminate us in the data, we no longer exist.”

– Abigail Echo-Hawk, Seattle Indian Health Board, *Science Magazine*, 2020

“We have perpetuated race as a category rather than a social construct, routinely inserting ‘race’ as an independent variable in statistical models, with ‘white’ invariably used as the reference category or default – the category from which all other racial outcomes are measured. Treating communities of color as derivatives of whiteness elevates whiteness above all else. We need to be explicitly critical and mindful of how we integrate the concept of race in our analyses and interpretations.”

– Cameron Okeke, Nancy G. La Vigne, *Urban Institute*, 2019

### STEP 5: Develop a plan to gather and analyze disaggregated data.

In recent years, a variety of organizations have been developing policy guidance documents to promote racial equity in data collected, stored, and used across the research lifecycle. Several address the structural biases and gaps in quality and accuracy of existing data sets while others recommend changes in the infrastructure and data systems that perpetuate these biases, ranging from national to organizational-level and local systems.

**Equitable data is the term used to describe disaggregating and analyzing data to identify and address disparities in federal policies and programs**

However, in all cases, the importance of data governance and stewardship strategy  $\frac{3}{4}$  the people, processes, and technology that ensure data security, integrity, quality, and disposition  $\frac{3}{4}$  must be top of mind for the research enterprise, even when governance structures operate in the background. Effective data governance leaders have strong analytic skills, deep understanding of privacy and security protocols, ability to communicate effectively across systems, and an appreciation for transparency when needed (Allen et al., 2014; Health Analytic Insights, 2021; Jamroz, 2023).

Below is a list of resources compiled to help you think through the ways your data management strategies, infrastructure, and systems can be improved to promote equity:

The [National Commission to Transform Public Health Data Systems](#) recommended several far-reaching strategies to improve data infrastructure; identify new data sources; and promote data

disaggregation to better identify risk and outcomes by race, gender, and ethnicity. The Commission was supported by The Robert Wood Johnson Foundation (RWJF), which followed up by funding several projects to accelerate progress in improving data systems by centering health equity narratives; prioritizing equitable governance and community engagement; and ensuring that public health measurement centers equity and reflects the impact of structural racism on communities (RWJF, 2021).

In a community-engaged model for data equity, 211/CIE® San Diego collaborated with Health Leads and others to develop a [CIE Data Equity Framework](#)® with support from RWJF and the California Children’s Trust (2023). The Framework focuses on how Community Information Exchanges (CIEs) can be leveraged for equitable and inclusive data and provides a landscape for data system design that characterizes the current state of systems, their impact on the communities they serve, and ways to engage with and empower communities.

Another [Data Equity Framework](#) developed by [We All Count Project for Equity in Data Science](#) takes a data democratization and data equity approach to data projects. In addition to their data equity framework, they have developed open access tools, training programs, a newsletter, and a community of practice. Along with training for individuals, teams, and organizations, they offer coaching and consulting services with field-tested scenarios and practical examples of ways to build trust through transparency through an intentional, equity-oriented process.

At University of Pennsylvania, Actionable Intelligence for Social Policy (AISP) released a [Toolkit for Centering Racial Equity Throughout Data Integration](#) (2020) which focuses on the importance

of building and maintaining data infrastructure with racial equity in mind throughout the data life cycle. To develop the toolkit, AISP convened a working group of civic data stakeholders to co-create strategies and identify best practices for reusing administrative data by government agencies, nonprofit organizations, foundation staff, and data collaboratives working toward the public good.

Focusing on health systems audiences, Grant-makers in Health and NCQA collaborated on a [Roadmap to Measure and Advance Health Equity](#), released in December 2021 with support from the Commonwealth Fund. After conducting an environmental scan and key informant interviews, they defined some key legal, technical, and cost barriers faced by health care organizations that influence the completeness and quality of race and ethnicity data. They also noted resistance from some patients and clinical providers about collecting racial/ethnic data. The recommendations to address these barriers include improving data collection strategies; providing financial support, incentives, and technical assistance; and clarifying and amending the regulatory infrastructure, e.g., privacy and security protections.

In 2023, [NCQA](#) expanded their health equity framework to include ways to advance standardized health equity equality measurement among state Medicaid programs, with support from the California Health Care Foundation. By using a common set of health equity quality measures across domains, public purchasers can promote accountability for equitable care measurement and reporting, which are fundamental to value-based payment.

Equitable data is the term used to describe disaggregating and analyzing data to identify and address disparities in federal policies and programs, and the Office of Technology Policy's National Science and Technology Council Subcommittee on Equitable Data (SED) is charged with operationalizing and scaling this goal. SED's March 2023 implementation report describes progress on several action items, including revising the [race and ethnicity standards used by federal agencies](#). These standards were set

in motion by the Equitable Data Working Group created in January 2022 by executive order; [their first report](#) was released in April 2022.

Across these resources, a series of practical steps will help researchers to promote a racial equity approach.

- Establish an equitable data governance plan and data use agreements with data-sharing and analytic partners.
- When using secondary administrative data (e.g., claims, surveys, etc.) evaluate how the data were generated and how your data aggregator processes the data.
- Interrogate your selection of a reference group when making comparisons among racial and ethnic groups.
- Determine what data are already available about your topic and assess the level of detail of racial and ethnic breakdowns (i.e., disaggregation).
- Determine whether those data are sufficient to answer your research questions in an equitable way or whether you will need to identify new partners and data sources.
- If you will be collecting primary data, ensure that people can “opt out” of providing data and use their feedback to minimize harm in future data collection (Hawn Nelson et al., p. 19).
- Negotiate fair and transparent data sharing agreements with partners, including community members from whom you collected data.
- Determine who will have access to the data and what security and privacy protections will be in place. Share that information in a transparent and understandable way with participants as part of the consent process (Wilbank, 2019).
- Determine how data will be stored and for how long. This is a concern with many communities of color, and particularly with indigenous people (Seattle Indian Health Board and Urban Indian Health Institute (2023); Haring et al 2021; Woodbury et al., 2019).
- Acknowledge data constraints, biases, and restrictions as part of the statement of understanding of the research problem. (See AISP 2020).

# QUESTIONS

1. What data equity framework are you using? Has it been developed and vetted by external sources?
2. Are your team members familiar with the terms “data democratization” and “decolonization of data”? How might those concepts be applied to your current work? (See 211 CIE San Diego, 2023; Payne et al., 2018; Haring et al., 2021; Magee et al., 2023; Tuhiwai Smith 2021; Urban Indian Health Institute, <https://www.uihi.org/projects/decolonizing-data/>).
3. Who will be negotiating your data use agreements? How will you ensure they are equitable? (See Haring et al., 2021, for guidance on equitable data use frameworks for indigenous communities.)
4. For qualitative data collection, do you have diverse voices developing your codebook and conducting qualitative coding?
5. Has your data training included diverse voices to promote consensus on data interpretations, and do you have a systematic process to resolve differences?
6. Have you discussed and been transparent about how you intend to act on any collected data and analyses to improve the lives of your study participants and partners?





“Despite decades of research exposing health disparities between populations and communities in the US, health equity goals remain largely unfulfilled. We argue these values call for applying an equity lens in the way we approach data systems, from collection and analysis to interpretation and distribution. Hence, health equity requires data equity.”

— Ponce NA, Shimkhada R, Adkins-Jackson PB, *Milbank Quarterly*, 2023

## STEP 6: Recognize intersectionality in your data collection and analysis plan

From a health policy perspective, it is challenging to evaluate health equity. **The Racial Equity and Policy (REAP) framework** developed by The Commonwealth Fund (Michener, 2022) is one approach to examining the ways the policy process impacts community health by asking questions about disproportionality (the ways policies allocate burdens and benefits); decentralization (how policy burdens and benefits are designed and implemented); and voice (the ability of the affected communities to influence the policy environment.)

### Health inequities do not happen in isolation.

From a research perspective, it is also challenging to evaluate health equity because of flaws and gaps in how data are collected, lack of standardized definitions, lack of access to data, concerns about privacy and legal issues, technical and organizational challenges with data sharing and interoperability, and many other barriers (see **Grantmakers in Health-NCQA**, 2021; O’Kane et al., 2021; **Network for Public Health Law**, 2022).

These challenges are not unusual in health and health-care research, but when assessing disparities and differential impacts, they are particularly concerning because the most marginalized communities are least likely to be reflected in the data and to be able to control how data about them are used (Hawn Nelson 2020; Kaiser Family Foundation, 2023; Petrovskis 2023). These data gaps make the communities invisible and less likely to be able to inform policies that affect them (Baker et al., 2021; Ponce, Shimkhada, Adkins-Jackson, 2023; Seattle Indian Health Board, 2023).

Alternatively, guidance from the **Assistant Secretary of Planning and Evaluation, US Department of Health and Human Services**, recommends an intersectional approach to advancing equity in research and analysis (US DHHS, 2022). Health inequities do not happen in isolation. Intersectionality refers to the complexity of lived experience, with people belonging to more than one group and having different identities. These differences among groups and identities may influence outcomes differentially and may not

be reflected in the data collected or the way they are analyzed unless they are addressed intentionally.

### The shift to an intersectional health equity lens will require innovation.

Applying an intersectional approach means looking at the complexities of differences in social status, privilege, and power that vary both within and between groups, then assessing the relative contributions of different influences and identities. **The National Academy of Medicine** sees the potential for intersectional approaches to more authentically study social drivers of health, eliminate disparities, and promote health equity and social justice. The shift to an intersectional health equity lens will require innovation in conceptualization, methodologies, and practices (Lopez & Gadsden, 2016; NAM, 2017).

Steps 7 and 8 of the Roadmap will describe data management and analytic strategies to address help recognize intersectionality and ameliorate structural bias. The following steps will position researchers to prepare for those activities.

- Identify potential sources of bias in data early on and be transparent about describing them as part of research methods sections as well as in discussions with community partners.
- In quantitative studies, consider leveraging methods to estimate impact of bias on study findings (Lash et al., 2016).
- Be aware of and be able to describe structural factors that are influencing your data, using language that’s appropriate for different audiences.
- Track the origins of where each element of data comes from and how it was produced, how it has been stored and accessed, and whether the data are still current (data provenance, or metadata) (We All Count, 2021).
- Ensure that the data you plan to report will be meaningful to the communities you are studying.
- Consider the ways your findings might be interpreted and used and the potential for unintended consequences, such as underestimates of disparities due to small sample sizes.

## QUESTIONS

1. How have you acknowledged the importance of a racial equity perspective in the data you are reporting on?
2. What tools and approaches are you using to support an intersectional perspective?
3. Have you traced the provenance of the data you will be using? (See We All Count Data Biography Template).
4. Have you included community members in defining your data collection and analysis agenda?
5. Are your data systems flexible enough to accommodate change as your study progresses?
6. Are your data systems accessible to those who are working on your study while protecting against data leaks and breaches of personal health information?
7. For qualitative research, are you noticing any patterns in coding and thematic analysis that might reflect implicit biases?



# Section IV:

## EQUITABLE INTERPRETATION AND DISSEMINATION

“There is often a conflation of race with racism in the interpretation of our research findings.”

– Rachel Hardeman and J’Mag Karbeah, *Health Services Research*, 2020

### STEP 7. Be transparent about data and analytic biases and limitations.

Previous sections of this Roadmap have highlighted ways to become aware of personal and professional biases in developing research questions, forming a team, choosing partners, and selecting and using different methods. This section focuses on how structural racism has led to biases that may be found throughout the data used for research, including vital and health statistics, survey data, and claims and clinical data from hospitals and health systems.

**Several researchers have noted that administrative data about racial and ethnic identity can be inaccurate and incomplete, producing biases in the analyses.**

Specifically, several researchers have noted that administrative data about racial and ethnic identity can be inaccurate and incomplete, producing biases in the analyses (Grantmakers in Health and NCQA, 2021; Hawn Nelson et al., 2020; Ponce et al., 2023). Implicit biases can include selection bias, in which the individuals included are not random or representative, and confirmation bias, in which data collection is skewed to confirm existing beliefs (Hawn Nelson et al., 2020). Other forms of bias with clinical implications include anchoring bias, the tendency to favor the first piece of information received; and informed presence bias, which assumes clinical differences between those whose information is included in an electronic health record (EHR) and those who are not included or who have multiple recorded clinical encounters (Goldstein BA, Bhavsar NA, Phelan M, Pencina MJ, 2016).

Another reflection of structural and systemic bias is when data are not collected at all from people from marginalized, racialized and ethnic groups. This renders them invisible in the data platforms used for policy decisions and challenges and confounds the accuracy of the data (Ponce et al., 2023; Seattle Indian Health Board and Urban Indian Health Institute, 2023).

Still another form of analytic bias is treating demographic data categorically, rather than using an intersectionality framework that acknowledges that a person can have different social identities that not only influence each other but can reflect existing social power structures (US DHHS/ASPE, 2022; Lopez & Gadsden, 2016). In other words, the architecture of the majority of data sets and systems does not reflect a racial equity perspective or recognize intersectionality, a key tenet of racial and social justice (Crenshaw, 2018; Hawn et al., 2020).

Further, the statistical methods used to compensate for the way the data are collected are not standardized or consensus-based. Some researchers replace missing racial/ethnic data by randomly selecting a value from a similar record, or by assigning an average of values from similar records. Others use advanced statistical imputation approaches from data science and statistics, which estimate race/ethnicity based on other available information. These approaches have raised concerns about accuracy, privacy, and lack of transparency (Brown, Ford & Ashley, 2021; Lines & Humphrey, 2021; Randall et al., 2021). Similar concerns are being raised for algorithmic bias in AI and machine learning (Benjamin 2019; Cabrerros, Agniel, Martino, Damberg & Elliott. (2022).

**Researchers can start now to use a racial equity frame and call out data equity concerns in their own work and in the data systems they use.**

At the federal level, an **Equitable Data Working Group** was created by executive order on the first day of the Biden-Harris administration to overhaul the federal data infrastructure with the goal of producing better racial/ethnic data. Equitable data is the term used to describe disaggregating and analyzing data to identify and address disparities in federal policies and programs. A March 2023 implementation report describes progress on several key activities, including revising the **race and ethnicity standards used by federal agencies**.

The **Centers for Medicare & Medicaid Services** also released a path forward report on advancing health equity through data standardization and improved data collection.

Over time, these standards will allow greater accuracy through disaggregation of small, distinct groups rather than rolling up small groups into a broader category or simply leaving them out. However, researchers can start now to use a racial equity frame and call out data equity concerns in their own work and in the data systems they use. This explicit attention will help to raise awareness about how structural biases in data sets and systems should be prevented in the future, and how to more fully interpret the current data.

Here are some ways to use a racial equity frame:

- Make it clear that a racial lens or framework informs the review and use of methods and data and be explicit about what that framework includes.
- Based on analyses of the provenance of data, describe any specific concerns about the limitations of data due to missingness or other flaws, including groups that might be misclassified or not represented.
- Include a data limitations statement in publications and public dissemination efforts. It should be written in culturally appropriate and accessible language.
- Ensure that the analytic team and/or advisors include previously marginalized researchers with different perspectives and sensitivities to bias.

## QUESTIONS

1. Are you familiar with best practices of establishing the history and source origin of the data you will be using?
2. When leveraging secondary data such as administrative claims, have you requested documentation on the provenance of racial and ethnicity data?
3. Are there demographic groups that you lack data for? Why?
4. How will you plan to fill data gaps and address missing data? How will you describe the approach you used to address missing data to community members?
5. Have you centered equity and intersectionality? If so, how do you describe it?
6. For qualitative research, what verification process do you have in place to help assure validity and reliability of your data? Do these processes involve verification with representatives from the populations that are involved in the research?
7. Have you included community members as co-authors in any publications?



“The academic publication process, through authors, reviewers, and editors, has legitimized scholarship that obfuscates the role of racism in determining health and health care.”

— RW Boyd, EG Lindo, LD Weeks, MR McLemore, *Health Affairs Forefront Blog*, July 2, 2020

## STEP 8: Broaden your thinking about dissemination.

In academic research, intended audiences are likely to be defined as readers of particular peer-reviewed publications, usually print and/or online journals and sometimes, depending on the outlet, blogs. The appeal of a particular journal may depend on its **impact factor**, calculated in terms of the frequency of citations of an average article and where the citations originate. Researchers submitting articles will also consider the journal’s acceptance rate, order of authorship, racial and ethnic diversity of the reviewer pool, and a host of other factors.

For those interested in disseminating to policymakers, written and online reports and policy briefs may be the more appropriate medium, preferably with some supporting peer-reviewed references and visually appealing graphics (see Ashcraft, Quinn, Brownson, 2020; Urban Institute, 2020). Researchers may be asked to provide in-person briefings and short summaries of key points using PowerPoint decks, data visualizations, infographics, and videos, usually with short turnaround-time due to time-sensitive policy decisions (Schwabish & Feng, 2021).

**Give public credit to partners and participants and create opportunities for them to co-design dissemination events, give presentations, and receive public recognition.**

Planning for dissemination can seem like an afterthought. However, the fields of implementation science, engagement science, and science communication agree on the importance of having a dissemination plan from early on in the project. Several sets of guidelines for developing plans have been developed.

- Nearly ten years ago, as part of its Translating Research into Practice (TRIP) initiative, the Agency for Healthcare Research and Quality (AHRQ) developed a planning tool to guide research dissemination to help improve patient safety.
- In 2014, AHRQ released a quick-start guide to dissemination for practice-based research networks that focuses on planning, identifying audiences, defining key messages, choosing communications vehicles, timing for different dissemination activities, and evaluating the dissemination.

- In 2015, PCORI released a dissemination and implementation framework and toolkit to increase public awareness of research evidence and help promote its integration into practice. The toolkit includes several detailed worksheets and other tools to help guide decision-making, while recognizing that every dissemination and implementation activity will be unique. PCORI also funds dissemination to increase public awareness and understanding of evidence.
- In 2022, the Career and Technical Education (CTE) Research Network released an Equity Framework for CTE Research, which includes a checklist for promoting equity at six stages of the research life cycle.

From a strategic communications perspective, choices about disseminating research findings depend on key audiences and other interested parties. What are they most interested in, where and how do they usually get their information, who are their most trusted sources, who do they want to hear from, and how can you make yourself accessible to their questions and feedback?

Equity researchers working with community members and community-based organizations may choose to submit their work to a peer-reviewed journal but because the time lag to publication can be significant, they typically may want to share preliminary findings with study participants and partners. These decisions about how much to share can be very challenging and depend on external factors such as the priorities of funders and the leadership of your own organization, the nature of the findings, the concerns of community partners, and many other considerations.

In approaching dissemination strategies, the following best practices may be helpful:

- Develop a dissemination plan early on and engage community partners and communications professionals in its development.
- Collaborate on development of public messages about your findings and test them with intended audiences.
- Give public credit to partners and participants and create opportunities for them to co-design dissemination events, give presentations, and receive public recognition.
- Seek out opportunities for funding community and patient partners to travel and participate in dissemination events.
- Use multiple communication channels and include a variety of visualizations, which are often easier for audiences to understand and remember.

# QUESTIONS

1. Have you developed a communication strategy that involves using universal terms and language? Have you explained technical jargon, and do you talk about social impact rather than or in addition to how your variables performed in your models?
2. Are your analyses dissemination-friendly? In addition to articles for publication, are you prepared to provide dashboards and summary statistics, summary graphics, other visuals such as infographics, and stories that reflect the values and imagery of the individuals and communities you engaged in your research?
3. Have you tested reports of preliminary findings with your team and community members?
4. What strategies will reduce or address potential for harm to communities when data are released?
5. Have you considered ways community members and partners can directly engage in dissemination activities, such as in presenting findings to policymakers or at local meetings and conferences?



“Nothing about us without us.”

—United Nations, *International Day of Disabled Persons*, 2004

## STEP 9. Approach dissemination and community engagement with cultural humility.

The nation’s data-driven health policy goals guide public health and community health goals and reporting, as described in [Healthy People 2030](#). For health plans, NCQA has defined ways that organizations can earn Multicultural Health Care Distinction. More than 57 organizations across the country have earned this distinction, providing care and services for more than 22 million people and tracking race/ethnicity and language data, providing language services, and developing programs and plans to eliminate health disparities.

Within health care systems, cultural humility is becomingly acknowledged as a deeper way to appreciate and improve the experience of all patients. For example, the Penn Medicine Experience Leadership Team (PMXLT) launched a campaign to incorporate cultural humility as a standard of care (others are compassionate, present, empowered, collaborative, and accountable). The year-long campaign was launched to help reinforce the importance of eliminating racism and implicit bias throughout health

**There is a lot to learn about how to address and engage with community leaders, patients, and advocacy groups.**

care, providing tools and materials, making sure staff know what names and honorifics to use with patients, and generating ideas for ways to help the patient and family experience align with their cultures.

In contrast, the health services and policy research community has no equivalent form of guidelines, standards, or certifications involving cultural humility. It is left to individual researchers and teams, and to the leadership in their institutions, to promote awareness and adopt the values and behaviors that

authentically express cultural humility. There is a lot to learn about how to address and engage with community leaders, patients, and advocacy groups in sharing findings they might have helped researchers to collect and analyze.

Most researchers think of dissemination primarily in terms of peer-reviewed publications and professional conference presentations. Some researchers agree to be interviewed and quoted in their institutions’ press releases after their work is published, but the work of dissemination to the communities and sharing findings from those who provided data may be an unplanned afterthought. Fortunately, some researchers in the emerging field of engagement science are reaching out to involve patients, community members, and other interested parties

**Community-centered dissemination toolkits emphasize dialogue with community members.**

as part of their research plans, especially when it is encouraged by funders (see Dungan et al., 2019).

In community-engaged research, best practices include communicating with community members throughout the entire research lifecycle from co-developing research questions to getting feedback on preliminary findings before dissemination. Community-centered dissemination toolkits emphasize dialogue with community members as a key part of the dissemination process (see CDC Global Health Equity Home (2022); McDavitt et al., 2016; University of Minnesota, 2021).

Intentional and authentic ongoing engagement with community partners and other interested parties takes time and resources. The incentives for engagement are not always aligned with other realities of the research enterprise, but community-engaged researchers have found that more authentic engagement can produce better science, more meaningful impact on communities, and a greater sense of professional satisfaction.

# QUESTIONS

1. How can the voices of the people you are studying be better represented when sharing findings with them?
2. Is your work freely accessible to the people you want to reach? Are you publishing key findings on web sites, in newsletters, and other local channels? Are you attending and presenting at community meetings and town halls with local leaders?
3. Have you used inclusive language and a glossary or guide such as a DEI toolkit with nontechnical language and graphics?
4. Have you cited researchers and community leaders who share the heritage and experiences of the people you studied?
5. Have community leaders expressed any concerns about dissemination of your findings? If so, has your team worked to address their concerns?
6. Have you developed strategies to work with community leaders to promote public awareness of your findings?
7. Do your products include graphics, color schemes, or wording that might reinforce stereotypes or unintentionally cause harm or blame (e.g., “Black patients do worse....”)? How can you reverse this?
8. Did you include historical context in explaining the statement of the problem you have studied?





# Section V:

## REFLECTION AND RENEWAL OF COMMITMENT TO A RACIAL EQUITY LENS

“The elimination of health inequities depends on the degree to which we invest in dismantling structural racism.”

—Zinzi Bailey, *Promoting Health Equity in Cancer Care*, 2017

### STEP 10: Acknowledge and share professional and personal learnings.

This Roadmap has aimed to show the impacts of structural racism on research from a racial equity perspective and to provide some suggestions about how to address structural biases and barriers in different research environments. Dozens of resources about diversity, equity, and inclusion in health systems are cited. Also included are guides to changing organizational culture to promote workforce diversity and innovation through multi-sector collaborations, using different frameworks, increasing self-awareness, and changing behaviors. We hope that reviewing the materials and engaging in discussions and self-reflection will help to uncover blind spots and biases and lead to insights about personal and organizational change.

**We hope that reviewing the materials and engaging in discussions and self-reflection will help to uncover blind spots and biases and lead to insights about personal and organizational change.**

One of the most comprehensive and thoughtful resources on racial equity is the volume [Necessary Conversations: Understanding Racism as a Barrier to Achieving Health Equity](#), edited by Alonzo Plough. As editor of the Robert Wood Johnson Foundation (RWJF) Culture of Health Series, Dr. Plough’s unique vantage point conveys the policy and political context of RWJF’s commitment to promote and support health equity and a culture of health among their grantees and the larger community of practice. The essays by thought leaders from a variety of research, public health, and clinical perspectives speak to the need to continually re-assess and refine professional and personal approaches to respectful, intentional engagement with others to build, promote, and sustain a culture of health.

In this Roadmap, we have aimed for a broad audience, including people who already have been working from a racial equity lens and those who are willing to have a conversation but are not yet engaged. Depending on where you live and work, and who you are, you may be more or less likely to have experienced the racialized nature of research culture first-hand. You may feel that the people around you are talking about diversity and inclusion but not doing enough to change the culture and their own behaviors.

You may have participated in DEI trainings, organizational retreats, healing spaces, book clubs, or other self-care and awareness-building activities about health equity. You may already have begun partnering with more diverse colleagues on different areas of interest, and you may be citing different sources from less familiar journals and areas of research. You may be the only one in your department or organization who has your areas of expertise and lived experience and may feel isolated by the white racial frame that dominates research culture.

**You may feel that the people around you are talking about diversity and inclusion but not doing enough to change the culture and their own behaviors.**

In the late 1990s, Tema Okun described 15 characteristics of white supremacy (white racial frame) along with possible antidotes. The list presented in Table 10-1 is frequently used in DEI trainings to help provide a framework for discussion, insight, and personal and organizational change. The list may be controversial or triggering, or it may bring a shock of recognition and familiarity. It may bring many other reactions as well. We believe this Roadmap would be incomplete without presenting the framework, and we encourage you to reflect on the characteristics as part of a racial equity lens for your own work and social environment.

As an example, the Montreal-based Centre for Community Organizations (2019) suggests ways for nonprofit learning organizations to interpret these antidotes to the white racial frame at an organizational level. They list questions for individuals and organizations to ask themselves, including these:

- How can we be open to learning on the job, making mistakes, and trying new things?
- How can we have a climate or culture that makes it easy for people to learn and change?
- How can we help ourselves learn to talk about very complex issues, especially where we have very little shared experience?

Of all the uncomfortable conversations in racial equity, one of the hardest is about naming the usually invisible ways the white racial frame runs through organizations. In their examination of racism in health services and policy research, Hardeman and Karberah (2020) describe how the premise of black inferiority and false biological beliefs about race legitimize white supremacy and perpetuate structural racism as a narrative and worldview. These equity researchers assert that we are in a moment where “the path forward compels us to change” (p. 780).

Signs of change are everywhere. The US Department of Health and Human Services has provided written guidance on incorporating intersectionality in research and analysis, including quantitative and qualitative approaches to embed equity at all stages of the research process (2022). The **National Science and Technology Council** (2023) reports progress in updating the federal standards for reporting equitable racial/ethnic data and making disaggregation the norm. Peer-reviewed journals such as *Health Affairs*, *HSR*, and *JAMA Network* have commissioned special issues and sections on health equity research. The National Academy of Medicine held a **workshop** on “unpacking racialization, intersectionality, and community” in July 2023.

Much more needs to be done. In the short term, we hope this Roadmap will spark new conversations, new actions, and new research methods and data sources. Over time, we also hope the Roadmap will contribute to culture change across the research enterprise. This transformation will require more opportunities for personal and professional sharing about what we’re learning, how it is changing what we do and how we do it, and how to look for supportive colleagues and communities (Rogers et al., 2023).

We look forward to your feedback and suggestions about how to continue doing this work. Please contact us at [DIME@academyhealth.org](mailto:DIME@academyhealth.org).

“Not everything that is faced can be changed, but nothing can be changed until it is faced.”

*James Baldwin, New York Times, 1962*

**Table 10-1: Characteristics of White Culture, based on (Okun, 2023; Centre for Community Organizations, 2019; Harvard Kennedy School).**

Characteristics	Antidotes
Perfectionism, such as pointing out how a person or their work is inadequate.	Instead, expect that everyone will make mistakes and that mistakes offer opportunities for learning
Sense of Urgency, such as prioritizing quick or highly visible results that can exclude potential allies.	Instead, discuss what it means to set goals of inclusivity and diversity, particularly in terms of timing.
Defensiveness, such as spending energy trying to protect power or defend against charges of racism.	Instead, work on your own defensiveness and understand the link between defensiveness and fear.
Valuing Quantity Over Quality, such as directing organizational resources toward measurable goals.	Instead, develop a values statement which expresses the ways in which you want to work, and make sure it is a living document that people apply to their daily work.
Worshipping the Written Word, such as valuing strong documentation and writing skills.	Instead, work to recognize the contributions and skills that every person brings to the organization.
Believing in Only One Right Way, such as concluding something is wrong with people who refuse to adapt or change.	Instead, never assume that you or your organization knows what's best.
Paternalism, such as decision-making processes that are only understood by those with power and unclear to those without it.	Instead, include people who are affected by decisions in decision-making.
Either/or Thinking, such as trying to simplify complex things.	Instead, slow down, encourage people to do a deeper analysis, and sense that things can be both/and.
Power Hoarding, such as feeling threatened when anyone suggests organizational changes.	Instead, understand that change is inevitable and that challenges can be both healthy and productive.
Fear of Open Conflict, such as equating the raising of difficult issues with being rude or impolite.	Instead, don't require those who raise difficult issues to do so in "acceptable" ways, particularly if you're using the ways in which issues are raised as an excuse not to address them.
Individualism, such as wanting individual recognition and credit.	Instead, make sure credit is given to everyone who participates, not just the leaders.
Believing I'm the Only One, such as thinking that if something is going to get done right, then 'I' have to do it.	Instead, evaluate people based on their ability to delegate to others.
Believing Progress is Bigger and More, such as defining success as hiring more staff, developing more projects, or serving more people.	Instead, make sure your own goals speak to how you want to work, not just what you want to do.
Believing in Objectivity, such as considering emotions to be irrational and destructive to decision-making.	Instead, push yourself to sit with discomfort when people express themselves in unfamiliar ways.
Claiming a Right to Comfort, such as scapegoating those who cause emotional or psychological discomfort.	Instead, welcome discomfort as much as you can and understand that it is the root of all growth and learning.

## APPENDIX 1: Glossary of Core Concepts and Definitions

**Allyship:** A strategy whereby people with unearned privilege (socially advantaged identities) partner with others to address patterns of injustice (APA, 2023; Kudlaca et al., 2020; Zheng, 2023)

**Asset-based framework:** An approach that focuses on assets and strengths of individuals and/or communities, such as their ability to maintain good health and reduce inequities, rather than emphasizing deficits, problems, and other shortcomings (California Health Care Foundation, 2021; Martin-Kerry et al., 2023)

**Centering whiteness:** Refers to prioritizing white feelings and interests over those of people of color. Decentering whiteness refers to creating and maintaining inclusive and intersectional perspectives that value, respect, and include those of people and groups that are marginalized by a white racial frame (Bledsoe, 2022; University of Minnesota Libraries, 2023).

**Diversity:** Refers to the identities we carry. There are many kinds of diversity, based on race, gender, sexual orientation, language, class, age, country of origin, education, religion, geography, physical or cognitive abilities, or other characteristics. Valuing diversity means recognizing differences between people, acknowledging that these differences are a valued asset, and striving for diverse representation as a critical step towards equity. (AMA and AAMC, 2021)

**Equity:** Refers to fairness and justice and is distinguished from equality. While equality means providing the same to all, equity requires recognizing that we do not all start from the same place because power is unevenly distributed. The process is ongoing, requiring us to identify and overcome uneven distribution of power as well as intentional and unintentional barriers arising from bias or structural root cause. (AMA and AAMC, 2021)

**Everyday racism:** Refers to routine, systemic, and familiar discriminatory practices that are normalized by mainstream society and can cause adverse psychosocial and physical effects such as hypertension and depression among racialized and marginalized people who are exposed (Essed 1991; Fujishiro 2008; Mahabir et al 2021; Oxford Reference 2023; Williams et al., 1997).

**Health equity:** Means that everyone has a fair and just opportunity to be as healthy as possible. (Braveman et al., 2022; The Robert Wood Johnson Foundation, 2022).

**Health equity tourism:** Describes the process of previously unengaged investigators becoming involved in health equity research without the requisite scientific expertise, thus perpetuating inequities and producing work that is not of a high quality (Lett, Adekunie, McMurray, Asabor, Irie, Simon, Harde- man, McLemore, 2022).

**Inclusion:** Providing equal opportunity to all people to fully engage themselves in creating an environment and a cultural attitude whereby everyone and every group feels accepted, has value, and is supported by a foundation based on trust and mutual respect. (Wright 2020).

**Intersectionality:** From a social justice perspective, a key tenet that refers to the way demographic information such as race/ethnicity, gender, and sexual identity interacts (intersects) with other characteristics to produce variations in experience. This perspective considers multiple intersectional social identities simultaneously to assess the impact of power, privilege, and discrimination (Crenshaw, 2018; Hawn et al., 2020; Zheng, 2023).

**Performative allyship:** Behaviors and expressions of support that are easy to do or say but do not change the status quo; primarily done for social acceptability and can be seen as superficial, misleading, disrespectful, or harmful (Kudlaca and Radke, 2022) <https://compass.onlinelibrary.wiley.com/doi/full/10.1111/spc3.12724#:~:text=We%20propose%20that%20the%20term,dessire%20to%20accrue%20personal%20benefits; Zheng, 2023>

**Positionality:** The perspectives or positions taken by researchers influence how they approach their work and specific topics they pursue. A positionality statement helps to clarify how their identities and experiences may be reflected in their work.

Roberts et al., 2020; University of Michigan Center for Disability Health and Wellness, 2023)

**Privilege:** Unearned, sustained benefits and advantages that come from belonging to a dominant social group including but not limited to race, class, gender, sexual identity, and ability. Privilege tends to be an unspoken and often unconscious advantage to those who have it, since the absence of privilege is what calls attention to it. (Cornell University DI Toolkit ([https://libguides.lib.msu.edu/c.php?g=1133877&p=8276231](https://scl.cornell.edu/DIpreface#:~:text=Privilege%3A%20Unearned%2C%20sustained%20benefits%20and,what%20calls%20attention%20to%20it; Michigan State University Libraries, DEI Resources: Power & Privilege))).

**Racial equity:** Concern with the direct impacts of structural racism on the health and well-being of people and communities of color as well as the ways in which racism intersects with other forms of marginalization, such as having low income, being an immigrant, having a disability, or identifying as LGBTQ+ or a gender minority (RWJF, 2022). A process of eliminating racial disparities and improving outcomes for everyone by prioritizing measurable change in the lives of people of color through intentionally and continually changing policies, practices, systems, and structures (Race Forward, 2023).

**Representation:** In the context of diversity, representation refers to the presence of variation in meaningful characteristics and dimensions such as demographics, gender, geography, stakeholder group membership, etc., where individuals' voices and opinions are respected and are seen to reflect power and authority. Their presence may increase credibility of the group both internally and externally (adapted from Zheng, 2023).

**Research lifecycle:** The multi-stage process of conducting research projects and studies from planning and designing to disseminating the findings (University of Colorado Boulder, 2022).

**Structural racism:** The normalization and legitimization of historical, cultural, economic, social, and legal structures, systems, policies, and beliefs that routinely provide advantages to white people and chronic and cumulative disadvantages to everyone else (Bailey et al., 2020; Braveman et al., 2022; Hardeman & Karbeah, 2020).

**White racial frame:** The dominant worldview held by most white people and many others that centers white people as the frame of reference for society, usually without conscious awareness. It perpetuates and reinforces racial stereotypes; increases tendencies toward discriminatory actions; uses racialized language and images; and maintains a negative orientation toward "others." (Feagin and Yancy, 2020; Hardeman & Karbeah, 2020).

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**STEP 2: Form a representative team that values communication, inclusion, and good management.**

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## Section II

### PREPARATION: FRAMING YOUR RESEARCH QUESTIONS

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### Section III

#### IMPLEMENTATION: DATA MANAGEMENT AND GOVERNANCE

##### STEP 4: Diversify references and data sources.

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